# THE EFFECTS OF ALZHEIMER'S DISEASE ON THE FAMILY CAREGIVERS: THE EMOTIONAL, SOCIAL, PHYSICAL, AND FINANCIAL IMPACT

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ABSTRACT

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**THE EFFECT OF ALZHEIMER'S DISEASE ON THE FAMILY CAREGIVERS: THE EMOTIONAL, SOCIAL, PHYSICAL, AND FINANCIAL IMPACT**

Advisor: Professor Mary Ashong

Thesis dated: May, 1990

Alzheimer's disease is a disease that is now believed to be the most single leading dementia in people over the age of 65. The disease is found in both sexes, all races, in people of every social economic and environmental background.

The purpose of the study was to examine the emotional, social, physical, and financial impact of Alzheimer's disease on the family caregiver and the burden they encounter as they attempt to cope with all these impacts.

The proportional random sampling method was used. All subjects in the investigation were actively participating in caring for a family member affected by Alzheimer's disease. Participants were obtained in the Atlanta area

chapter of the Alzheimer's Association. The sample consisted of fifty primary caregivers of patient diagnosed with Alzheimer's disease. The ages of the caregivers ranges from 40 - 75 years. The caregivers were siblings, daughters, and spouses of the patients.They were all from different socio-economic backgrounds.

A variety of statistical methods were used to describe and analyze the data collected. Some of the techniques include simple descriptive tables, measurement of variables, and measures of central tendencies. The Chi Square measure of statistical differences and correlational analyzes and Duncan's multiple range were also used

The key findings of the study indicated that lack of money to care for the patient has the greatest emotional impact on the caregivers. Level of Education determines the degree of tolerance of the family caregiver. The most significant of these profiles is the emotional impact. Thus, the social and physical are also significant.

Since the emotional impact is so stressful and causes instability, certain therapy indicated in the study would be appropriate if administered to the family caregivers.

DEDICATED TO MY FAMILY

My children, Chijioke, Chukwudi, and their father, Lambert Madu. Ajieren, and my sister, Doris Brown Onyenucheya, for their encouragement, understanding, love, cooperation, and forbearance. Without their contribution, this thesis would not have been possible.

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Above all, to the fifty wonderful and courageous caregivers who so graciously participated in my study, thank you, my heart is with you all.

Finally, thank God, I made it.

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# Chapter I

## Introduction

(A) General overview of the study:

Alzheimer's Disease is a disease that is now believed to be the most single leading dementia in people over the age of 65. The disease is found in both sexes, all races, in people of every social, economic and environmental background (Roach, 1985). Alzheimer's usually begins in later life, but individuals in their 50's, 40's and even younger have been diagnosed with Alzheimer's disease (French, Morrison, & Levine, 1985).

A German neurologist named Alois Alzheimer was the first to describe the disease in 1906. However, very little research was done in this area until research was again pursued by three British scientist in the 1960's (Roach, 1985). But the symptoms have been documented in literature and medical textbooks for hundreds of years. The recognition of Alzheimer's as a disease has occurred as a result of medical and scientific discoveries. National and local effort to increase public awareness by the Alzheimer's disease and Related Disorders Association (ADRDA) has also been significant in bringing the disease to the

attention of the community. Today more than 3 million Americans are known to be affected (Teusink and Mahler, 1984).

Alzheimer's disease, or dementia of the Alzheimer type is the most common dementing illness (Leroux, 1981). According to the Alzheimer's disease and related Disorders Association, there are 2.5 million people in this country with Alzheimer's and by the turn of the century one family in three will have some member with the disease (Pyrillis, 1986). Williams (cited in Pyrillis, 1986) has estimated that 4.4% of people over 65 who are residing in the United States show moderate to severe dementia, and 65% of this group is believed to have Alzheimer's disease.

Alzheimer's disease involves a multifaceted loss of intellectual abilities, as such as memory judgements, abstract thought, and other higher functions and changes in personality and behavior. It is a basically clouded state of consciousness. As a result, families of these patients are faced with an ongoing grief process and will most likely need continuing support and intervention to cope with this devastating illness. The onset of Alzheimer's in people is usually gradual, involving slow physical and

mental let down. In some cases a physical ailment or some other stressful event is a dividing point, but usually the individual passes into a psychotic state almost inperceptibly, so that it is impossible to date the onset of the disorder precisely. The symptoms often begin with the individual's gradual withdrawal from active engagement with life (Coleman, Butcher, and Carson, 1984). Often there is a self centering of thoughts and activities.

Investigators are uncertain whether AD is an infectious process, a toxic condition, a biochemical deficiency, or an acceleration of normal aging. The possibility that it is a metabolic syndrome has been considered, and blows to the head have been thought to be of etiologic significance in some cases. There are indications of geographic differences in the prevalence of Alzheimer's disease which if confirmed, would suggest that environmental factors are involved (Mozar, H., Bal, D., and Howard, J.).

(B) Statement of the problem:

Among the most intense and interpersonally demanding situations in which individuals can find themselves is that of providing care for a relative with Alzheimer's disease or a related brain disorder

(Cohen, D., Eisdorfer, D.). Families assume the major burden of care and institutionalize relatives only when their emotional, physical, or financial resources are exhausted. The care giving role requires round-the-clock vigilance and family members must adjust normal family routines and cope with many changes and uncertainties during long years of caring. They report chronic fatigue and feeling of anger, resentment, guilt, self-doubt, frustration, helplessness, and depression (Robins, P. V., Mace, N. L.,and Lucas, M. J., 1982, and Zarit, S. H., Reeves, K. E., and Boch-Peterson, J., 1980).

(C) <u>The effects of AD on the caregiver:</u>

According to Wiley (1983), by viewing the family as a ''static entity in which tasks are assigned to its members'' (p. 271); the integrity and functioning of the family would depend upon the fulfillment of these tasks. Any disability would result in disruption on task assignment and performance, and further result in disintegration of the family system. Based upon this framework, it is assumed that any catastrophic event, including an illness such as Alzheimer's disease, which affects a particular family member would also affect the entire family, disrupt it's

equilibrium, and result in the type of disintegration described above (Stanley, R. 1987).

Major caregivers, primarily spouses, or family member living with an older relative with Alzheimer's disease experienced physical, emotional depression, and financial exhaustion (Cohen, 1988).

Individuals caring for a family member with AD may feel angry that they have been trapped into long-term caregiving roles, and that the sick person behaves in an irritable and ungrateful manner. Certain family members may be resentful that others are not assisting with care. Family members often cannot accept the fact that the victim may have no control over frustrating behaviors.

Guilt is a very common emotional reaction for a variety of reasons, losing one's temper, resenting the responsibility, considering nursing home placement, feeling that the burden of care can no longer be handled and unresolved conflicts from the past may cause feelings of guilt. Very common, too, is the feeling that the caregiver is responsible for the deterioration of the person, even though everything possible is being done for the patient.

Time away from the victim may also arouse guilt

in a family member. Caregivers may become cut off from social activities and other outside interest. The health and quality of life for the caregiver may be jeopardized (Nornes, B. F., 1981).

The Alzheimer caregiver is often called the hidden, or second, victim of AD. The physical results of caregiving stress can be fatigue, stomach problems, headaches, and difficulty sleeping. The emotional stress of caregiving can cause depression, tension, anger, guilt, loss of self-esteem, and feelings of being overwhelmed. In addition, many caregivers think that others can not understand how they feel or may think that their feelings are unacceptable. Unfortunately, most caregivers do not recognize the association between the stress of caregiving and their physical and emotional symptoms.

Caregiving also changes the relationship between the caregiver and the patient. In addition to providing care, the caregiver must accept the patient's previous responsibilities. In some cases, the caregiver's image of themselves may change. Perhaps they never used to scream, and now find that their frustration results in frequent screaming episodes. Adding to this stress are the financial

difficulties that generally accompany AD.

One of the most frequent problems is encountered when family members care for a debilitated relative involves the shifts which occur in familiar roles when an adult child must become the caregiver for a demented parent. The stress of the apparent role reversal can be severe (Brody, 1985). A simple task, such as assisting the AD victim with bathing, can come to symbolize the new role and the caregiver may pour all of the associated stress into resenting or fearing that task (Mace & Robins, 1981). These role changes are frustrating and disruptive to everyone involved (Mace & Robins, 1981). Closely related to this problem of role shifts is the necessity of making decisions for the person.

Responsibilities for caregiving affect everyone in the family to some degree. If one person avoids sharing in the responsibility, that decision has a potential effect on everyone. The spouse caregiver, for example, may feel in need of assistance from adult children who are too far away, too busy, or too distress by the situation to actively help. Guilt, resentment, isolation, and frustration become part of the dynamics of the family (Straw, L. B., 1987). The decision making

processes within the family are distorted by these issues, which can in turn hamper appropriate care for the patient.

(D) The Purpose of the Study:

The purpose of this study is to examine, within a frame work of family system theory, whether or not Alzheimer's disease places a heavy burden on the persons who care for the patients of the disease as well as understanding the role of formalized social services and how it intends to supplement and help strengthen the family's ability to meet the needs of their patients.

The majority of demented patients are cared for in their homes by family members, not in institutions. The family caregivers often turn to the physicians or their team for help in dealing with the burden they encounter as they attempt to cope with the physical, social and emotional issues that arise in the care for a person with Alzheimer's disease. In addition to the stresses of caring and being cared for when one is disabled by dementia, the onset and progress of a chronically debilitating disorder provoke psychological issues that were previously unresolved and may not have otherwise arisen were it not for a

stress of this magnitude. Issues relating to dependency, aggression, guilt, and loss are among the more common ones seen in patients and caregivers. Some families require significant interventions whereas other have adequate coping skills and need relatively little. Most families require continuing support from medical or health professionals (Billing, N., 1988).

## Chapter II

## Literature Review

(A) Over the past ten years, Scientist have made significant advances in understanding Alzheimer's disease (AD). Research also has been directed not only to looking for the cause of AD and its cure, but to looking for better diagnostic procedures, treatment for AD related problems and ways to cope with the effects of the disease.

The ultimate goal is a cure. Until one is found, research will continue to seek an improved quality of life for individuals with AD and their families (AD and related disorders Association Inc. 1987)

Alzheimer's disease is a degenerative disease affecting nerve cells of the frontal and temporal lobes of the cerebrum of the brain. The disease is the major cause of presenile dementia (i.e. the loss of mental faculties not associated with advanced age) and is thought to be the largest single cause of senile dementia as well. Among its effects are speech disturbances and severe memory impairment leading to the progressive loss of the mental faculties. No effective treatment was available by early 1980s.

Alzheimer's disease was first described by Alois

Alzheimer using the case of a 55-year-old woman who died with severe dementia. After the women's death, Alzheimer was able to examine her brain and noted changes which are regarded as characteristic of the disease which now bears his name. These changes a senile plaques, a structure that had been described previously in the brains of elderly persons. It is now known that plaque is composed of degenerating nerve terminals, reactive glial cells (non-nervous cells present in nerve tissue), and fibrous material called amyloid. The second abnormality noted by Alzheimer was the neurofibrillary tangle, a fibrous structure within nerve cells, which showed up heavily with the use of a silver stain. The neurofibrillary tangle had not been described before, and it was principally this abnormality that defined a new disease entity. Until fairly recent times, Alzheimer's disease was regarded as a very rare disorder affecting people under the age of 65 only. Because it occurred in people who had not reached the conventional point of old age, it was described as a presenile dementia. At this time, dementias occurring in the elderly were labelled as senile dementias. These are much more common than the presenile Alzheimer's disease, and were generally

thought to be due to cerebral atherosclerosis or narrowing of the arteries supplying blood to the brain (Britannica, 1989). The brain was seen as being strangled of its blood supply because of diseased arteries, resulting in progressive dementia. However, autopsy studies on the brains of people with senile dementia , carried out in the 1960s and 1970s, showed that they in fact exhibited the characteristic features of Alzheimer's disease (Alzheimer's Association Inc. 1985).

It then became usual to refer to the these people as suffering from senile dementia of the Alzheimer type. In more recent years, there has been a tendency to refer to all cases as Alzheimer's disease, irrespective of whether the disorder occurs before or after age 65 (Jorm, A.F., 1987).

Alzheimer's disease is very much a disorder of the elderly. For instance, only relatives who have lived to old age will have had a change to develop the disorder. Thus, it is possible to look for Alzheimer's disease in parents and siblings, but children of affected individuals are generally too young to have a chance to develop it.

Despite all this information, there is now good

evidence that parents and siblings of Alzheimer's disease cases do have a greater risk of developing the disorder (Heston, 1981, Heyman et al., 1983; Whalley et al., 1982) Probably the most thorough study of family history is that of Heston (1981) in Minnesota, who studied the families of a large number of cases of autopsy-proven Alzheimer's disease. He found the risk to parents of these cases as being 15-23 percent and the risk to siblings as 10-14 percent. However, these general risk estimates are rather misleading because Heston found that the risk to relatives varies greatly depending on the age at which Alzheimer's disease began.

Of all the changes due to aging and/or disease associated with aging, deterioration of brain function has the greatest negative impact upon the individual, the family, the community, the health care system, and society at large. Approximately 5-7% of people over 65 years of age and 20% over 80 years of age suffer from Alzheimer's disease, which accounts for more than 50% of all senile dementias. Approximately 1.3-1.8 million Americans over 65 suffer from Alzheimer's disease. Another 80% or more in their 40s and 50s, also suffer from this disease (Burns B.M, Buckwalter K.C, 1988).

The emotional cost of the family and caregivers and the financial burden to the family and to the society are staggering.

Although Alzheimer's disease affects a small proportion of the older population, for every one person who suffers from the disease, there are many other persons in the individual's social network who are affected. For instance, family members of the Alzheimer's sufferer are directly involved in caregiving and support (Sheldon F, 1982). Of the immediate family, one member usually takes on the primary responsibility for care, a task that may become an overwhelming emotional and physical responsibility. Often the primary caregiver, because of age or other responsibilities is not able to meet the demands of a chronic stressful situation, and in the process, may jeopardized his or her own physical and mental health. Unfortunately, although the physical health care needs of the patient are addressed by families and professionals, the social-emotional and support needs of the caregiver are often not recognized or given attention (Barnes R.F, Raskind M.A, Scott M., et al: 1981). Those caregivers who care for someone with Alzheimer's disease will need help in

giving that care and in caring for themselves as well. Not everyone will need the same services to the same degree. But almost everyone will need some services for some period of time (Cohen D., Eisdorfer, C. 1986).

The most elusive aspect of early onset of Alzheimer's disease is that it does not always present itself in the same way. There is great individual variation. One should not assume that the only early signs of AD are memory problems. It is essential to have memory plus something else wrong. For example, memory plus a language problem, memory plus apraxia, memory plus visual-spatial misperceptions. In other words, you have got to establish that indeed the individual does have a condition where multiple cognitive functions show clear evidence of deterioration over time while consciousness itself is apparently unimpaired (Colerick E.J., George, L.K., 1986).

Major Theoretical Orientation:

The Theoretical model that will be frame-work for study is the part dealt with the effect of Alzheimer's disease on the family or caregivers. Behavioral model of health services utilized and developed by Robert J.

Havighurst (1972) was be used. The basic model assents that health services use a function of (1) Adjust and free self from guilt and resentment, (2) Relate to victim as a person, (3) Accept and adjust to decreasing physical strength and health, (4) Adjust to reduced income, and (5) Establish affiliation with support groups for family caregivers of patients with Alzheimer's disease.

*See the next page*

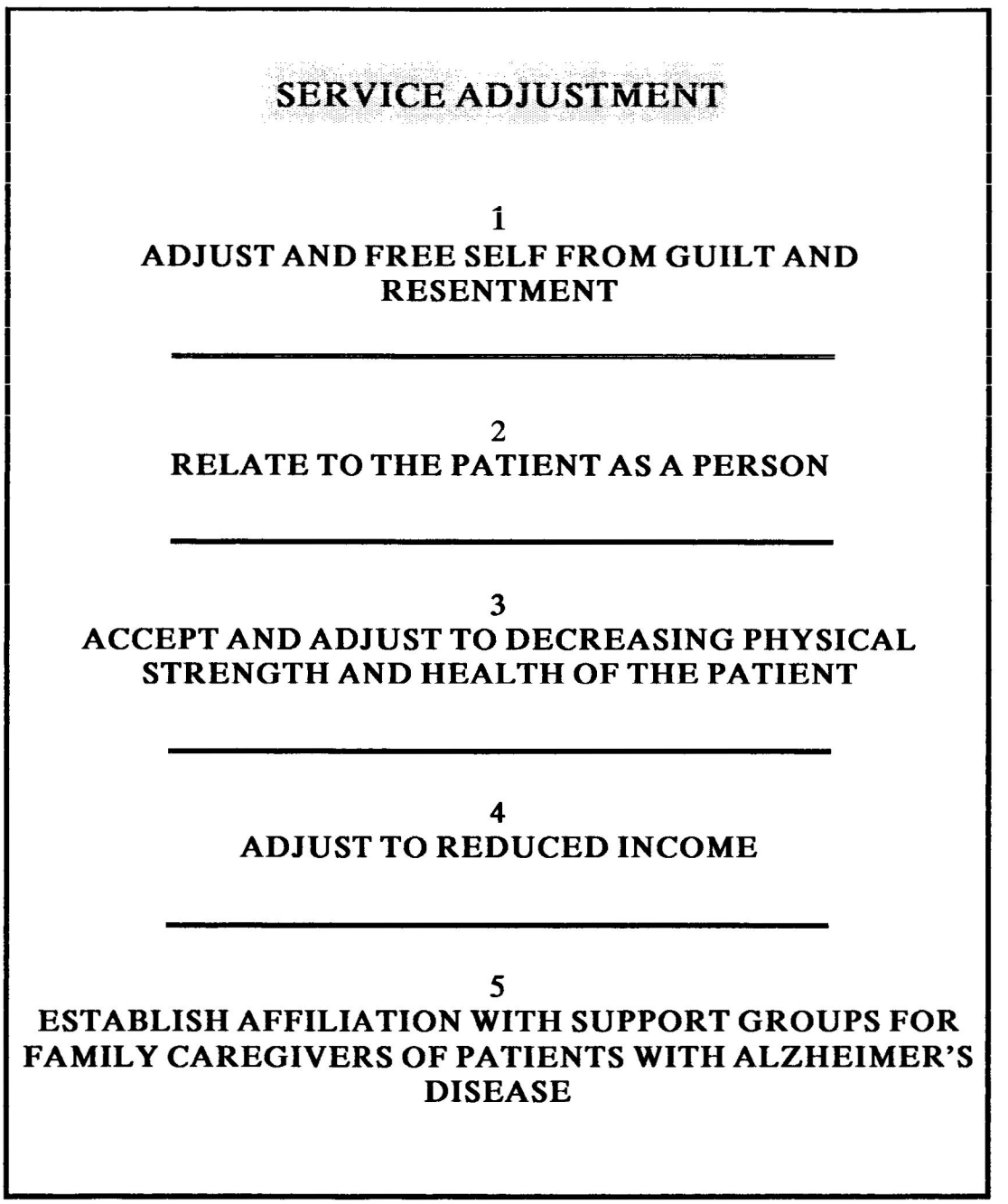


Fig. 1 Behavioral Model of Health Service Utilization.

Adjust and free self from anger, guilt and resentment:

Families of persons with Alzheimer's disease often feel guilt, anger and resentment. Individuals may feel angry that they have been trapped into long-term caregiving roles, and that the sick person behaves in an irritating and ungrateful manner. Certain family members may be resentful that others are not assisting with care. Family members often cannot accept the fact that the victim may have no control over frustrating behaviors.

Guilt is a very common emotional reaction for a variety of reasons. Losing one's temper, resenting the responsibility, considering nursing home placement, feeling that the burden of care can no longer be handled and unresolved conflicts from the past may cause feelings of guilt. Very common, too, is the feeling that the caregiver is responsible for the deterioration of the person, even though everything possible is being done for the patient.

Time away from the victim may also arouse guilt in a family member. This can be especially acute for spouses. Caregivers may become cut off from social activities and other outside interests. The health and quality of life for the caregiver may be jeopardized because of this responsibility.

Relate to the patient as a person:

Do not talk about the person as though he or she is not there. Assume that the person can understand what is being said. Do not laugh at inappropriate behavior or speech.

Accept and adjust to decreasing physical strength and health of the patient:

The most difficult new role for a spouse or adult child is that of total care provider and decision maker. A caregiver must take on responsibilities that were formerly performed by the victim of Alzheimer's. In most cases, the caregiver lacks the preparation for assuming the social role traditionally provided by a person of the opposite sex. The adult child may feel sadness at the loss in the parent's ability to care for him/herself and feel guilty about taking over for some one that he or she formerly looked to for assistance. Most role changes occur gradually and painfully. One of the major difficulties is knowing the appropriate time to take over responsibilities from the victim.

Because the damage of Alzheimer's is not physically visible, the patient often looks healthy. While this could be considered a positive aspect of

the disease, it may create the problem of having others, including family, fail to realized that the person is ill and may need special attention and supervision.

Adjust to reduced income:

An individual's ability to use health care depends on his or her family resources such as income, health insurance, regular care, geographic location and so on.

The Alzheimer's victim may be terminated from a job or forced into early retirement because of work inadequacies caused by the disease. The caregiver of an Alzheimer's patient may be required to resign early from employment in order to provide the care needed for the patient. In both cases the amount of income available to the family is reduced, either from lost wages or decreased retirement income.

Establish affiliation with support groups for family caregivers of patients with Alzheimer's disease:

It is safe to assume that all self-help and support groups get their strength from the comfort of members' sharing their perceptions with others who are going through a similar experience. Participation reduces one's sense of being alone in the world. For

many, it is only in this group that they feel they are really understood, and they are probably right in most cases. Even the most skilled and empathic professional does not have the same level of understanding as a person who lives the ''36-hour day'' (Mace, N.L., and Rabino, P.V. 1981).

(B) Definition of Terms:

**Alzheimer's Disease:** Is the major form of untreatable, irreversible dementia. This disorder of the brain cells cause progressive degenerative changes in brain tissue. Alzheimer's is a neurological disease which results in gradual, total helplessness.

**Dementia:** A condition of deteriorated mentality.

**Degenerative disease:** To pass from a higher to a lower type or condition.

**Cerebrum:** The front part of the brain, concerned with thought and decision.

**Senility:** Senility is the word which has been commonly used to describe the loss of mental abilities in older persons. However, ''senility'' is a term which has no medical meaning. A loss of mental abilities has erroneously been thought to be a normal part of aging, but only about 10 to 15 percent of

people over 65 suffer from severe loss of mental functioning.

**Elderly:** Individual aged 65 or older.

**Neurofibrillary tangle:** A fibrous structure within nerve cells.

(C) Statement of Hypothesis:

The researcher does not intend to study the cause of Alzheimer's disease nor does she intend to focus on the treatment of the disease. The purpose of the study is to investigate the emotional, physical, financial and social impact on the family member caregivers of Alzheimer's disease and to determine if there was a correlation between persons who participate in a caregiver support group and non-participant .

The results of this research may demonstrate the usefulness of support group and the social work implication with caregivers of Alzheimer's disease patients.

The main hypothesis of the study is:

1. Several preliminary expectations were made for the present investigation in anticipation of two primary hypothesis. First, it was expected that impact would be positively correlated with emotional, physical, financial impact as well as social impact.

## Chapter III

## Methodology

This chapter presents the research design, the sampling method, the data collection procedures and a description of the statistical methods used in the study.

Research design:

The purpose of this study was to examine the impact of Alzheimer's disease on the family caregivers. To be able to answer the research questions validly and objectively, current and complete data on the burden caregivers encounter as they attempt to cope with the physical, social and emotional was needed.

To collect the data, an analysis of secondary survey method was used.

Sampling Method

A proportional random sampling method was used. All subjects in the present investigation were actively participating in caring for a family member affected by Alzheimer's disease. Participants were obtained in Atlanta Area Chapter Alzheimer's Association. The chapter cooperated in the present study by allowing the investigator to use information

given by the caregivers regarding research participation.

The sample consisted of fifty primary caregivers of patients diagnosed with Alzheimer's disease.

Characteristics of the Sample:

The caregivers were related to the patient as follows: fifteen daughters of female patients, ten daughters of male patients, six male spouses, eleven female spouses, and eight female sisters of female patients. The ages of the caregivers ranged from 40 to 75 years old.

At the time of this study thirty-five of the patients were living at home with the family caregiver. Six families were in the process of considering the possibility of an outside placement for their patient. Five of the patients had been placed in a nursing home; and four had died during 1989. Each caregiver had attended a support group at least once while caring for the patient in their homes.

The family caregivers were asked to complete a detailed questionnaire that related to their general frame of mind and to the over all effects of the situation (i.e., demographic characteristics, mental and physical health, lifestyle and health promoting

behavior, perceptions of stress, well-being, social and recreational activities, financial resources, knowledge of Alzheimer's disease, social support, use of community services, and coping strategies).

Data Collection Procedures:

The main method of the data for the study was collected by using a questionnaire developed specially for the purpose. Before this instrument was used, it was tested and examined for validity. Permission from the agency was sought and obtained. Assistants who were to help collect the information from the caregivers were trained in order to maintain consistency in interpretation and responses.

Data Analysis:

A variety of statistical methods were used to describe and analyze the data collected. Some of the techniques includes simple descriptive tables, measurement of variables, and measures of central tendencies. The Chi Square measure of statistical differences and correlation analysis were also used.

# Chapter IV
## Presentation of Results

Proposed Hypothesis for Emotional Impact

1) $H_o$: There is no significant difference between Alzheimer's disease on family caregivers and emotional stability.
2) $H_A$: There is a relative significant difference between Alzheimer's disease and family caregivers and emotional stability.
3) $H_A$: There is no significant relationship between Alzheimer's disease on family caregivers and emotional stability.

**Table 1**
**Cell Means and Standard Deviations**

| Variables | Mean | Variance | Standard Deviation |
|---|---|---|---|
| Unable to cope | 1.440 | .823 | .907 |
| Stress | 1.920 | .483 | .695 |
| Lack of time for self | 1.560 | .781 | .884 |
| Lack of privacy | .440 | .578 | .760 |
| Stress with patient | .680 | .874 | .935 |
| Health problem | 1.900 | .582 | .763 |
| Lack of money to care for patient | 2.100 | 1.113 | 1.055 |
| Inability to take care of patient | 1.440 | .904 | .951 |
| Loss of control | 1.520 | .540 | .735 |
| Future | 2.020 | .387 | .622 |

Study #I (Emotional Impact)

Subject

Fifty family caregivers were involved with this study. The questionnaire consisted of ten variables concerning the emotional impact of Alzheimer's disease on the family caregivers.

Results

All responses were scored independently and the data collected were analyzed by using SPSS - language. The mean of the independent variables were compared to each other using Duncan's Multiple Range Comparisons method. The result of this analysis indicated the degree of the emotional impact on the caregivers. The Tables 1 through Table 4 are based on the analysis of the emotional impact on the family caregiver of the Alzheimer's disease.

Study II (Physical Impact)

The subjects were the same as that of Study I. However, the questionnaire consisted of thirteen independent variables concerning the physical impact on the family caregivers.

Test

All responses were collected independently and the collective data were analyzed using SPSS - language.

The analysis were performed with orthogonal - abstract so that Duncan's Multiple Range method can be employed to the hypothesis test. Please refer to the Table 5 through Table 7 for this analysis. The conclusions were implored from the analysis of data collected. The validity of this study is based on the responses collected from the fifty subjects involved in the study.

Results

The conclusion indicates the degree of impactness of physical on family caregivers.

Study III (Social Impact)

The same number of subjects were involved in this study with eighteen independent variables. The questionnaires were then standardized by the appropriate department before administered.

Test

All responses were scored independently as indicated in the studies I and II but coded differently. The data collected were analyzed using SPSS - language. The analysis computed are shown in Table 8 through Table 10. The validity of the different degrees of social impact is based on the fifty subjects tested.

Results

The conclusions indicate that social impact on the family caregivers are as significant as emotional and physical impact. However, the degree of impact socially varies.

Emotional

The Duncan's Multiple Range Test is used in testing for the significance of the mean of the emotional profile: The following is ranked in ascending order.

**Table 2**

**Significance of the Mean of the Emotional Profile**

| Variable Descriptions | Symbols | Means |
|---|---|---|
| Lack of privacy | $\bar{Q}_4$ | .440 |
| Stress with patient | $\bar{Q}_5$ | .680 |
| Unable to cope | $\bar{Q}_1$ | 1.440 |
| Inability to take care of patient | $\bar{Q}_8$ | 1.440 |
| Loss of control | $\bar{Q}_9$ | 1.520 |
| Lack of time for self | $\bar{Q}_3$ | 1.560 |
| Health problem | $\bar{Q}_6$ | 1.900 |
| Stress | $\bar{Q}_2$ | 1.920 |
| Future | $\bar{Q}_{10}$ | 2.020 |
| Lack of money to care for patient | $\bar{Q}_7$ | 2.100 |

The results of computations are summarized as follows:

**(Table 3)**

**Results of Computations**

| P | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|
| $r_p$ | 2.829 | 2.976 | 3.073 | 3.143 | 3.198 | 3.241 | 3.277 | 3.307 | 3.333 |
| $R_p$ | 3.513 | 3.699 | 3.823 | 3.898 | 3.972 | 4.022 | 4.072 | 4.109 | 4.134 |

Emotional

Comparing those least significant ranges with the differences in ordered means, I arrive at the following conclusions:

1. Since $\bar{Q}_7 - \bar{Q}_4 = 1.660 < R_{10} = 4.134$, I conclude that $\bar{Q}_7$ and $\bar{Q}_4$ are not significantly different.
2. Comparing $\bar{Q}_7 - \bar{Q}_5$ and $\bar{Q}_{10} - \bar{Q}_4$ with $R_9$, I conclude that $\bar{Q}_7$ is significantly greater than $\bar{Q}_5$ and $\bar{Q}_{10}$ is significantly greater than $\bar{Q}_4$.
3. Comparing $\bar{Q}_7 - \bar{Q}_1$ and $\bar{Q}_{10} - \bar{Q}_5$ and $\bar{Q}_2 - \bar{Q}_4$ with $R_8$, I conclude that $\bar{Q}_7$ is significantly greater than $\bar{Q}_4$, $\bar{Q}_5$, and $\bar{Q}_1$.
4. Comparing $\bar{Q}_7 - \bar{Q}_8$, and $\bar{Q}_{10} - \bar{Q}_1$, $\bar{Q}_2 - \bar{Q}_5$ and $\bar{Q}_6 - \bar{Q}_4$ with $R_7$,I conclude that $\bar{Q}_7$ and $\bar{Q}_{10}$ are significantly greater than $\bar{Q}_8$, $\bar{Q}_1$, $\bar{Q}_2$ and $\bar{Q}_5$.
5. Comparing $\bar{Q}_7 - \bar{Q}_{10} = 0.08$ , $R_2 = 3.513$, I conclude that $\bar{Q}_7$ and $\bar{Q}_{10}$ are not significantly different. In other words the emotional impact on caregivers are equal.

6. However, $\bar{Q}_7$, $\bar{Q}_{10}$, $\bar{Q}_2$ and $\bar{Q}_6$ constitute a subset and homogeneous means.
7. I observed from the means of each profile computed for the emotional impact of Alzeheimer's disease on caregivers that there is no significant difference between lack of privacy and stress with patients; and unable to cope and inability to take care of patient.
8. The degree of emotional impact can be categorized this way; $\bar{Q}_7 > \bar{Q}_{10} > \bar{Q}_2 > \bar{Q}_6 > \bar{Q}_3 > \bar{Q}_9 > \bar{Q}_8 > \bar{Q}_1 > \bar{Q}_5 > \bar{Q}_4$. In other words lack of privacy is the least significant compared to lack of money to care for the patient.

**Table 4**

**Analysis of Variance of Emotional Impact**

| Source of Variation | Sum of Squares | Degrees of Freedom | Variance |
|---|---|---|---|
| Unable to cope | 144.007 | 49 | .823 |
| Stress | 207.987 | 49 | .483 |
| Lack of time for self | 159.949 | 49 | .781 |
| Lack of privacy | 38.002 | 49 | .578 |
| Stress with patient | 65.946 | 49 | .874 |
| Health problem | 209.018 | 49 | .582 |
| Lack of money to care for patient | 275.037 | 49 | 1.113 |
| Inability to take care of patient | 147.976 | 49 | .904 |
| Loss of Control | 141.980 | 49 | .540 |
| Future | 222.983 | 49 | .389 |

Thus the Variances of the independent variables for the emotional impact are tested as follows: using table 4: Unable to Cope/Stress = .823/.483= 1.7 - 2

1. Implies that Unable to Cope is more significant then the stress imparted on the caregivers by the Alzeheimer disease.
2. The ratio of lack of time for self has more impact on the caregivers than the emotional stress.
3. Since the ratio of lack of time for self and lack of privacy are constant, implies that there is no significant difference between them.

4. Lack of money to care for the patient has the greatest emotional impact on the family caregivers then any of the variables.

Proposed Physical Impact Study on Caregiver Families

$H_o$: There is no significant relationship between the Alzheimer disease on family caregivers and physical impact.

$H_A$: Alzheimer's disease had positive physical impact on family caregivers.

$H_A$: Alzheimer's disease has negative physical impact on family caregivers.

The following are among the many ways a family caregiver may be evidently involved.

* Interesting Life
* Lack of Understanding
* Inability to Cope
* Insanity
* Happy
* Useful
* Healthy
* Headache
* Balance
* Lonely
* Worry
* Daily Routine
* Situation (perhaps from feeling rejected)

**Table 5**

**The Means and Standard Deviation of the Profile**

The table below compares the mean of different physical impacts on caregivers

| VARIABLE DESCRIPTION | MEAN | VARIANCE | STANDARD DEVIATION |
|---|---|---|---|
| Interesting life | 1.840 | .137 | .370 |
| Lack of understanding | 1.400 | .245 | .495 |
| Inability to cope | 1.660 | .229 | .479 |
| Insanity | 1.300 | .214 | .463 |
| Happy | 1.880 | .108 | .328 |
| Useful | 1.440 | .251 | .501 |
| Healthy | 1.560 | .251 | .501 |
| Headache | 1.300 | .214 | .463 |
| Balance | 1.840 | .178 | .422 |
| Lonely | 1.680 | .222 | .417 |
| Worry | 1.360 | .214 | .463 |
| Daily routine | 1.260 | .196 | .443 |
| Situation | 1.300 | .214 | .463 |

**Table 6**

**The Ranking of the Means in Descending Order**

| Variable Description | Symbols | Means | Rank |
|---|---|---|---|
| Happy | $\bar{Q}_5$ | 1.880 | 1 |
| Balance | $\bar{Q}_9$ | 1.840 | 2 |
| Interesting life | $\bar{Q}_1$ | 1.840 | 2 |
| Lonely | $\bar{Q}_{10}$ | 1.680 | 4 |
| Inability to Cope | $\bar{Q}_3$ | 1.660 | 5 |
| Healthy | $\bar{Q}_7$ | 1.560 | 6 |
| Useful | $\bar{Q}_6$ | 1.440 | 7 |
| Lack of Understanding | $\bar{Q}_2$ | 1.400 | 8 |
| Worry | $\bar{Q}_{11}$ | 1.360 | 9 |
| Situation | $\bar{Q}_{13}$ | 1.300 | 10 |
| Insanity | $\bar{Q}_4$ | 1.300 | 10 |
| Headache | $\bar{Q}_8$ | 1.300 | 10 |
| Daily Routine | $\bar{Q}_{12}$ | 1.260 | 13 |

Comparing these least significant ranges with the differences in ordered means, I arrive at the following conclusions:

1. The physical impact on the caregivers is more significant in terms of the happiness. In other words the physical impact on the caregiver's happiness is more significant than any other variables.
2. The least significant variable is the physical impact on the daily routine.

3. Thus $\bar{Q}_5 > \bar{Q}_9 > \bar{Q}_1 > \bar{Q}_{10} > \bar{Q}_3 > \bar{Q}_7 > \bar{Q}_6 > \bar{Q}_2 > \bar{Q}_{11} > \bar{Q}_{13} > \bar{Q}_4 > \bar{Q}_8 > \bar{Q}_{12}$ classify the degree of physical impact on the caregiver's family. In other words $\bar{Q}_5$ had the greater impact and $\bar{Q}_{12}$ the least impact.
4. Loneliness and worriness have equally significant physical impact of the caregiver's family.

**Table 7**

**Analysis of Variance of Physical Impact**

| Source of Variation | Sum of Squares | Degrees of Freedom | Variance |
|---|---|---|---|
| Interesting life | 45.273 | 49 | .137 |
| Lack of understanding | 110.005 | 49 | .245 |
| Inability to cope | 149.001 | 49 | .229 |
| Insanity | 94.986 | 49 | .214 |
| Happy | 182.012 | 49 | .108 |
| Useful | 115.979 | 49 | .251 |
| Healthy | 133.979 | 49 | .251 |
| Headache | 94.986 | 49 | .214 |
| Balance | 178.002 | 49 | .178 |
| Lonely | 151.998 | 49 | .222 |
| Worry | 103.995 | 49 | .235 |
| Daily routine | 88.984 | 49 | .196 |
| Situation | 94.986 | 49 | .214 |

However, the Variances of the independent variables for the physical impact are tested as follows: thus using table 7:

$F_{.05,1,49}$ = 4.06 the F - ratio = $S_1^2/S_2^2$ = .245/.137 = 1.788.

1. Since F - ratio = 1.788 < F - distribution = 4.06, I conclude that there is no significant difference between the physical impact of Lack of Understanding and Interesting life of caregivers.
2. Comparing the physical impact of Inability to Cope and Insanity, I conclude that there is no significant difference between them.
3. The physical impact on the caregivers happiness is the most significant compared to the rest of the variables, however, loneliness and worriness are equally significant.
4. I conclude that physical impact on the family caregivers is very important and physical stability in a varying degrees are indicated above as being significant.

Proposed Hypothesis for Social Impact

1. $H_o$: There is no significant difference between the degree of Social impact and Alzheimer disease on family caregivers.
2. $H_A$: There is a relatively significant relationship between the degree of social impact and Alzheimer disease on family caregivers.

3. $H_A$: There is relatively no significant relationship between the level of social impactness and Alzheimer disease on family caregivers.

The following are projected as a social impact on family caregivers as a result of Alzheimer disease:

* Age (the age of the family caregivers)
* Sex (sex of the family caregivers)
* Race
* Marital Status
* Education
* Relationship to client (the relationship of the caregiver to the patient)
* Length of caring (duration of the caring for the patient)
* Attendance support group (number of times attended)
* Respite services
* Standard of living
* Health status
* Method of payment
* Employment status (nature of caregivers profession)
* Work Schedule (how often do they engage in working)
* Household income (income of the caregivers)
* Family members assistantship
* Living arrangement

**Table 8**

**Social Ranking Means:**

**The Ranking of the Means in Ascending Order**

| Variable | Symbols | Means | Rank |
|---|---|---|---|
| Attend Support Group | $\bar{Q}_8$ | 1.580 | 1 |
| Sex of family caregiver | $\bar{Q}_2$ | 1.600 | 2 |
| Living arrangement | $\bar{Q}_{18}$ | 1.660 | 3 |
| Employment status | $\bar{Q}_{14}$ | 1.700 | 4 |
| Race of caregiver | $\bar{Q}_3$ | 1.980 | 5 |
| Standard of living | $\bar{Q}_{11}$ | 2.000 | 6 |
| Times attending | $\bar{Q}_{10}$ | 2.220 | 7 |
| Work schedule | $\bar{Q}_{15}$ | 2.280 | 8 |
| Pre health status | $\bar{Q}_{12}$ | 2.480 | 9 |
| Marital status | $\bar{Q}_4$ | 2.600 | 10 |
| Relationship to client | $\bar{Q}_6$ | 2.760 | 11 |
| Method of payment | $\bar{Q}_{13}$ | 2.800 | 12 |
| Length of caring | $\bar{Q}_7$ | 2.920 | 13 |
| Age of caregivers | $\bar{Q}_1$ | 2.960 | 14 |
| Income of caregivers | $\bar{Q}_{16}$ | 3.040 | 15 |
| Family assistantship | $\bar{Q}_{17}$ | 3.100 | 16 |
| Attend support group | $\bar{Q}_9$ | 3.540 | 17 |
| Educational Background | $\bar{Q}_5$ | 5.520 | 18 |

The following conclusions are implored from table 8:

1. There is no significant difference between Attendant Support Group and Sex of family caregivers socially.
2. Living arrangements and Employment Status of caregivers are equally significant.
3. Race of caregivers and the standard of living are equally significant in the social life of family caregivers.
4. Work schedule and Number of times attendance show no significant difference in the social life of caregivers.
5. Health Status and Marital Status demonstrate no significant difference, however, they are more significant then age, sex, race and, living arrangement of the social life of family caregiver.
6. Income of caregiver is more significant then marital status in the social life of caregiver.
7. Educational Background is greatly significant in the social aspect of caregivers of Alzheimer's disease than any of the projected social impact. In other words the social stability is based on the degree of the family caregiver.
8. Attendant Support group is the least significant in the social life of the family caregivers.

9. $\bar{Q}_5 > \bar{Q}_9 > \bar{Q}_{17} > \bar{Q}_{16} > \bar{Q}_1 > \bar{Q}_7 > \bar{Q}_{13} > \bar{Q}_6 > \bar{Q}_4 > \bar{Q}_{12} > \bar{Q}_{15} > \bar{Q}_{10} > \bar{Q}_{11} > \bar{Q}_3 > \bar{Q}_{14} > \bar{Q}_{18} > \bar{Q}_2 > \bar{Q}_8$. This trend demonstrates the degree of social impact on the life of family caregivers.

**Table 9**

**The Mean and the Standard of the Social Impact on Family Caregivers**

| Variable Description | Mean | Variance | Standard Deviation |
|---|---|---|---|
| 1. Age of caregiver | 2.960 | 1.713 | 1.309 |
| 2. Sex of caregiver | 1.600 | .245 | .495 |
| 3. Race | 1.980 | .632 | .795 |
| 4. Marital status | 2.600 | 1.143 | 1.069 |
| 5. Education | 5.520 | .458 | .677 |
| 6. Relationship to client | 2.760 | 1.493 | 1.222 |
| 7. Length of caring | 2.920 | 1.626 | 1.275 |
| 8. Attendance Support Group | 1.580 | .249 | .499 |
| 9. Respite Service | 3.540 | 3.233 | 1.798 |
| 10. Number of times attending. | 2.220 | 1.360 | 1.166 |
| 11. Standard of living | 2.000 | .000 | .000 |
| 12. Pre-Health status | 2.480 | 1.357 | 1.165 |
| 13. Method of payment | 2.800 | 2.490 | 1.578 |
| 14. Employment status | 1.700 | .663 | .814 |
| 15. Work Schedule | 2.280 | 1.430 | 1.196 |
| 16. Household income | 3.040 | 1.550 | 1.245 |
| 17. Family member assist. | 3.100 | 1.888 | 1.374 |
| 18. Living arrangement | 1.660 | .841 | .917 |

**Table 10**

**Analysis of Variance of Social Impact**

| Source of Variation | Sum of Squares | Degree of Freedom | Variance |
|---|---|---|---|
| Age of caregiver | 522.017 | 49 | 1.713 |
| Sex of caregiver | 140.005 | 49 | .245 |
| Race | 226.988 | 49 | .632 |
| Marital status | 394.007 | 49 | 1.143 |
| Education | 1545.962 | 49 | .458 |
| Relationship | 454.037 | 49 | 1.493 |
| Length of caring | 505.994 | 49 | 1.626 |
| Support Group | 137.021 | 49 | 1.580 |
| Respite Service | 704.000 | 49 | 3.233 |
| Number of times | 313.060 | 49 | 1.360 |
| Standard of living | 0.000 | 49 | .000 |
| Pre-Health status | 374.013 | 49 | 1.357 |
| Method of payment | 514.010 | 49 | 2.490 |
| Employment status | 176.987 | 49 | .663 |
| Work Schedule | 329.990 | 49 | 1.430 |
| Household income | 538.030 | 49 | 1.550 |
| Family assist. | 573.012 | 49 | 1.888 |
| Living arrangement | 178.989 | 49 | .841 |

Using the Table 10 for the analysis of Variance the following conclusions are implored:

1. Respite Services are very significant in the social life of the family caregivers.
2. Method of Payment is as insignificant in the social impact of the family caregivers of the Alzheimer diseased patients as the age of the caregivers.
3. However, the least significant of these projected social impacts is the standard of living.
4. The F-distribution is 4.02 and the F-ratio computed for the Respite Services to the Method of Payment is 1.2984,therefore, since the F-computed is less than the F-distribution, there is no significant difference between these projected social impacts.

Results

Using Duncan's Multiple Range Comparisons of the emotional, physical, and social means, the result of this analysis indicated that the *lack of money to care for the patient* has the greatest emotional impact on the caregivers compared to both the physical and social impact.

The least significant of all these impacts is *lack of privacy*. However, *level of education* determines the

degree of tolerance of the family caregiver. The most significant of this profiles is the emotional impact. Thus, the social and physical are also significant. The findings also indicated that there is no significant difference between loneliness and loss of control of the family caregivers. The F computed from findings indicated the level of the significance between physical, emotional, and social impact. Thus, the validity of this findings is based on the data collected. Since the emotional impact is so stressful and causes instability, certain therapy would be appropriated if administered to the family caregivers. The collective effort between the caregivers may promote mutual interaction and psychological stability. Furthermore, government interference in finding the cure or helping the family members will free many souls from experiencing emotional agony. Service should be provided to these families before they collapse under the strain of caregiving.

## Chapter V

## Implications for Social Work Service

Social work services for the Alzheimer's patient are intended to supplement and strengthen the family's ability to meet the needs of the family member with Alzheimer's disease. Social worker interventions that are designed to reduce stress, increase coping, and eliminate the negative impact of the immediate situation. The caregivers need ongoing support and availability of crisis assistance. Families often need information about Alzheimer's disease and the developmental stages in order to enable them to effectively solve problems and make decisions. The caregivers need the opportunity to express their feeling of anger, resentment, guilt, frustration, or sorrow. May be, if the individual is not given a chance to recognize and express his/her feelings, these feelings can in turn affect the caregiver's ability to deal with the situation. As social workers, we must provide the interventions for the family/individual and the skills necessary to succeed in the tasks of caring for themselves and their family member with Alzheimer's disease.

Safford in 1980 implemented an educational and

support program for families of the Alzheimer's disease patients which was conducted over a three-year-period at the Isabell Geriatric Center in New York City. Caregivers received intensive training for two hours a week over a six-week period. Participants received practical knowledge about the nature of mental impairment and learned how to supervise and care for the patient in the home. The family members also had the opportunity to discuss their individual problems. This three-year project demonstrated that intensive, short-term training of caregivers was quite effective.

Beaulieu and Karpinski in 1981 describe a group treatment program for well-elderly with ill spouses. The group treatment process focuses on the personal needs of the caregivers, and the group experience helps spouses adapt positively to the changes in their lives that result from the incapacity of their partners. In this kind of therapy, group members can learn how to share their hopes, fears, depression, anxieties, and frustrations with others who understand these feelings. Such groups can help to prevent the emotional deterioration of the caregiver.

The social worker can help the caregiver learn how to guide the patient's daily behaviors by giving

him/her careful and clear instructions about such matters as how to supervise the patient's eating, bathing, dressing, and performing of tasks around the house. When the patient requires some physical assistance with these tasks, it is important for the social worker to help the family provide the kind of care that will maximize the patient's functioning and minimize his/her dependency. This involves providing the minimal level of direct assistance to the patient. Bayne in 1978 stresses that the initial step in treatment should be to mobilize the patient's own control mechanisms.

Eisdorfer, Cohen, and Preston in 1981 state that operant reinforcement procedures can be effective in changing or modifying some of the patient's problems with verbalization, motor behaviors, and self-care. The social worker can teach the family how to select and apply the most effective positive reinforcers on a day-to-day basis. Attempts can also be made to arrange elements within the physical environment, the timing of family routines, and social interactions in such a way that the cues for specific functional behaviors are as clear to the patient as possible. A modified version of the reality orientation approach can be used in the

patient's home. Providing the patient with factual information about her or himself and the environment helps to minimize confusion.

Caring for the severely mentally impaired person like Alzheimer's disease in the home can be physically and emotionally taxing. The psychological impact on the caregiver can be profound. The patient's change in personality is usually the most upsetting factor for the caregiver. This personality deterioration is more destructive of the quality of family life than the patient's physical disability (Coni, Davison, & Webster, 1980).

In clinical work with families of Alzheimer's patients, three phases have been noticed in professional counseling: (1) an education phase where families need to know about and understand the disease; (2) a problem-solving stage where they learn various ways to manage patient's inappropriate behaviors and fully capitalize on their remaining abilities (minimize unrealistic expectations and maximize patient functioning); and (3) an effective stage where families begin to recognize and come to terms with how they feel about the changes in their elderly family member and their caregiving role. In addition, such counseling and

support (individually or in groups) may help not only in alleviating problem severity, but in identifying additional social support and encouraging the utilization of the support.

The clinical social worker can play a significant role in the provision of hospice care. The social worker's capacity to be empathic, genuine, and respectful facilitates the patient's and family's coming to terms with the reality of death. The social worker may be called upon to assist the patient in making a decision about where and when to die.

Social work plays a significant and central role in long-term care practice. A recently emerged interventive function provided by the trained social worker in long-term care is that of service case management. This multi-role function incorporates the basic steps of the generic process of psychosocial systems intervention-primary, secondary, and tertiary.

Service case management including the casework counseling component is applied in a variety of different agencies that serve the Alzheimer's disease patients in the community. Protective service agencies, home-health agencies, and day-care programs comprise a major portion of the community-based, long-term care field.

The long-term care social worker makes a valuable contribution to the informal caregivers of the Alzheimer's disease patients. They train family caregivers to be more effective in their caregiving, and serve as advocates and brokers for needed, quality services from the formal systems of care. The social worker uses supportive therapy to help ease the psychological burden experienced by many caregivers. Direct treatment of the impaired persons in the home is frequently provided to promote the best possible level of psychosocial functioning.

# Chapter VI

## Summary and Conclusion

A qualitative study was conducted with fifty primary caregivers of patients with Alzheimer's disease. The purpose of the study was to determine, through the framework of Family Systems Theory, whether or not impact would be positively correlated with emotional, physical, social and financial impact.

The analysis of the data revealed that while each caregivers responded in a unique way, there were many similarities and differences reported among them. However, people typically cope with, and adapt to difficult situations, and respond to support, by employing the various type of strategies customarily used in their particular family system. Thus, support groups may be perceived as valuable by some, while not so by others. According to this study only 10% of the participants perceived support groups as beneficial. This assumption was substantiated by the responses of the fifty caregivers of Alzheimer's patients who participated in the study. The report shows that support groups are not necessarily perceived as valuable by all caregivers.

The Emotional Impact:

Regardless of family background, the caregivers all reported some distress with regard to the complete loss of freedom they were experiencing. Although, some tended to minimize their feelings with regard to this.

Other common feelings reported were sadness, both for their love ones, and for themselves, loneliness for the loss of this other person, their former companion, spouse or parent, and resulting depression. Role changes were described as having had an extremely stressful effect on the caregivers.

All of the caregivers typically reported feelings of strain, stress, burden, or fatigue, at one time or another. However, some of them denied many of these feelings, quickly placing the focus on the needs of the patient, as well as on their own need to fulfill what they considered to be their duty as a caregiver.

Physical Impact

Self neglect, and various kinds of stress related symptoms, such as heart disease, high blood pressure, stroke, and a nervous stomach, were attributed to the impact of the disease. Other themes reported or expressed were worry about what was going to happen to the patient next; what the subsequent levels of the

disease might bring; anxiety and apprehension for themselves, their own health, as well as for that of the patient; and concern over what would happen if the patient were to outlive them.

Financial Impact:

Lack of money to care for the patient has the greatest emotional impact on the family caregivers than any of the variables. Because the caregivers were of similar socio-economic level, there were many commonalities among their description of the financial impact of the illness. Most of them described the ''crunch'' of being in a middle income bracket. While being above a level to be eligible for various types of social assistance on the one hand, on the other hand they were forced to face the reality of being unable to afford the tremendous drain in finances the illness had brought. Another great common concern among them was the inadequacy of private health insurance programs, as well as Medicare, for a long-term illness. In addition, because of the income level of the caregivers, their patients are considered ineligible for Medicaid, which might otherwise have paid for nursing home costs. Most of these expenses were related to increased medical costs. In some cases, however, the expenses had to do

with moving and resettling in a more affordable dwelling or moving geographically closer to another family member.

Social Impact:

Many of the caregivers described feelings of social isolation, due to the withdrawal of former friends; as well as, in some cases, family members. However, social isolation appeared to be self-imposed in several instances, by the caregiver's withdrawal from outside contact, rather than by the withdrawal of others.

Limitations of the Study

It was not possible for this study to address in-depth the difference between persons who participate in a caregiver support group, this issue is very important for social workers toward improving the kinds of resources available to families in this situation.

It would be interesting to conduct a research on examining the influence of the family system on the various basic coping strategies. Perhaps this might be of great value in assisting family caregivers of Alzeimer's disease.

Further research should also include or consider finding the reason some people are willing, and often

eager to reach out for assistance, and emotional support while others are not.

Suggestions For Future Research

1) The psychological correlation of Alzheimer's Disease need to be researched.
2) Does a person's family background influence the way they perceive, cope with , and adopt to catastrophic events.
3) The caregiver's particular Family System may influence the way in which they perceive the value of support group.

Additional research with a larger and more varied population is also needed.

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# APPENDIX A

Atlanta University
School of Social Work
J.P. Brawley At Fair St.
Atlanta, Georgia 30314

Dear Sir/Madam:

My name is Adline Fuller, and I am a graduate student at Atlanta University School of Social Work specializing in clinical social work. First, I thank you for allowing me to use your service. The area of concern is to try to examine the attitudes and feelings of persons who help provide or monitor the care of family members who are victims of Alzheimer's disease.

I have been interested over the years in how family caregivers of patients with Alzheimer's disease manage to care for their love ones. Alzheimer's disease is an illness that may effect 4 out of 20 families and is a problem that needs to be understood by social workers.

The information I collect will be compiled and reported to other professions. I believe this is an

important step toward improving the kinds of resources available to families in this situation.

Participation in the project involves completing a survey designed to reflect your own thoughts, feelings and opinions. The questions relate to your general frame of mind and the overall effects of the situation. No identifying information will be requested, and all information pertaining to the study will remain completely confidential.

If you have any questions or concerns about the project, please contact me at the above address.

Thank you for your time and effort.

Sincerely yours,

Adline Fulller

# APPENDIX B

Study I (Emotional Impact)

## Questions

1) Is your daily life full of things that keep you interested?
2) Does it seem that no one understands?
3) Have you had periods of days or weeks when you couldn't ''get going''?
4) Is your sleep disturbed?
5) Are you happy most of the time?
6) Do you feel useless at times?
7) During the past few years, have you been well most of the time?
8) Are you troubled by headaches?
9) Have you had difficulty in keeping your balance walking?
10) Even when you are with people, do you feel lonely most of the time?
11) Do you worry because you no longer feel good about yourself or take pride in what you're doing?
12) Do you feel that things you used to do occasionally to help out are now part of your daily routine?
13) Do you see yourself going on in a no_win situation just to avoid admitting failure?

## Scoring

Responses were scored as follows: Yes = 2 No = 1

Study II (Physical Impact)

Questions

1) During the past six months, how many times have you seen a doctor for your physical health? (*This should not include doctors seen while an inpatient in a hospital or nursing home*).

___ (0) 0 times

___ (1) 1-2 times

___ (2) 3-5 times

___ (3) 6 or more times

2) During the past six months how many days were you so sick that you were unable to carry on your usual activities - such as going to work or working around the house? *(This should not include days spent in a hospital or nursing home)*.

___ (0) 0 times

___ (1) 1-2 times

___ (2) 3-5 times

___ (3) 6 or more times

3) During the past six months how many hospital stays did you have for physical health problems?

___ (0) 0 times

___ (1) 1-2 times

___ (2) 3-5 times

___ (3) 6 or more times

4) Do you currently take any medication for nerves, depression or to help you sleep?

___ (0) 0 times

___ (1) 1-2 times

___ (2) 3-5 times

___ (3) 6 or more times

Scoring

Responses were scored independently and scored for each subject's 50 responses. A specific variable earned points.

| Points | Response |
|---|---|
| 0 | 0 times |
| 1 | 1-2 times |
| 2 | 3-5 times |
| 3 | 6 or more times |

StudyIII (Social Impact)

Questions

(Part 1)

1) Age____

2) Sex

1. Male

2. Female

3) Race

1. White

2. Black

3. Other

4) Marital Status

1. Never
2. Married
3. Widowed
4. Divorce/Separated
5. Remarried

5) Levels of education obtained

1. Sixth grade or less
2. Seventh, eight, and ninth grades
3. Partial high-school (tenth, and/or eleventh)
4. High-school graduate
5. Partial college or specialized training (at least one year)
6. Standard college or university degree
7. Masters, professional, or doctoral degree

6) What is your relationship to client?

1. Husband
2. Wife
3. Son
4. Daughter
5. Friend
6. Sibling
7. Other, please state.

7) Are you currently:

1. Employed
2. Retired
3. Homemaker
4. Unemployed but seeking or would like to work
5. Other _____

8) As a result of the care provided, has the primary caregiver had to : (circle one)

1. Reduce the number of hours worked?
2. Rearranged work schedule?
3. Take time off without pay?
4. Leave a job?
5. Does not know

9) Estimated Household income

1. Less than $5,000 per year
2 $5,000 - $10,000 per year
3. $11,000 - $19,000
4. $19,000 - $29,000
5. $30,000 or more.

10) Does the family currently get assistance from other family members or friends in helping take care of the patient?

1. Does not receive help
2. Occasional
3. 1 to 4 hours per week
4. 5 to 9 hours per week
5. 10 to 15 hours per week
6. More than 15 hours per week
7. Not applicable

11. Living arrangement

1. My Alzheimer's patient lives with me in my residence.
2. My patient lives with another relative or friend.
3. I live with my Alzheimer's patient in his/her residence.
4. My patient lives in:
    a. nursing home
    b. home for adults
    c. State Mental Hospital
    d. veteran hospital
    e. other

(Part 2)

1) Do you feel you can no longer cope with the situation?
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
3) Do you feel that because of the time you spend with your patient that you don't have enough time for yourself?
4) Do you feel that you don't have as much privacy as you would like because of your patient?
5) Do you feel stressed when you are around your patient?
6) Do you feel your health has suffered because of your involvement with your patient?
7) Do you feel that you don't have enough money to care for your patient, in addition to the rest of your expenses?
8) Do you feel that you will be unable to take care of your patient much longer?
9) Do you feel you have lost control of your life since your relative's illness?
10) Are you afraid of what the future holds for your relative?

(Part 3)

1) During the past week how many times did you spend time with someone who does not live with you; that is, you went to see them or they came to see you or you went out to do things together?

___ Once a day or more

___ 2-6 times

___ Once

___ Not at all

2) In the past week about how many times did you talk to someone_friends, relatives, or others on the telephone (either you called them or they called you)? *(If subject has no phone, question still applies)*

___ Once a day or more

___ 2-6 times

___ Once

___ Not at all

3) How satisfied are you with the visits/calls you get from family and/or friends?

___ (0) Very satisfied

___ (1) Satisfied

___ (2) Unsatisfied

___ (3) Very unsatisfied

4) How often do you attend church ar religious services?

___ Regularly

___ Occasionally

___ Rarely

___ Never

5) If you do not attend on a regular basis, how often would you like to attend church or religious services?

___ (0) Never

___ (1) Rarely

___ (2) Occasionally

___ (3) Regularly

6) How often do you attend meetings of social groups, clubs, or civic organizations?

___ Regularly

___ Occasionally

___ Rarely

___ Never

7) If you do not attend on a regular basis how often would you like to attend meetings or social groups, clubs or civic organizations?

___ (0) Never

___ (1) Rarely

___ (2) Occasionally

___ (3) Regularly

8) How many hours a week do you spend on recreation or personal hobbies?

___ More than 10 hours

___ 5-10 hours

___ 1-5 hours

___ 0 hours

9) How satisfied are you with the amount of time you spend in recreational activities or on your personal hobbies

___ (0) Very satisfied

___ (1) Satisfied

___ (2) Unsatisfied

___ (3) Very unsatisfied

10) Do you attend Alzheimer's Association support group meetings?

___ Regularly

___ Occasionally

___ Rarely

___ Never

11) Who told you about this Program?

12) Have you ever considered a nursing home placement for your relative?_____

*Adopted from the Suncoast Gerontology Center*

Scoring

Responses were scored as follows:

For parts 1 and 3 the score appears after each question in parentheses. The scoring for part 2 is as follows:

0 = Never; 1 = Rarely; 2 = Sometimes; 3 = Frequently